

Spirituality as a coping method for mothers of children with developmental disabilities

Aysel Karaca  and Dilek Konuk Şener

Duzce University, Faculty of Health Science, Duzce, Turkey

Mothers of children with developmental disabilities suffer from tremendous stress and anxiety. These mothers may use religion and spirituality as coping mechanisms to help them adjust to changes emerging in their lives as well as to resolve problems. This study evaluated the spiritual needs of mothers of children with developmental disabilities and analyzed the effect of spirituality on their lives. This is a descriptive and qualitative study carried out at the School for Children with Mental and Physical Disabilities in Turkey. The study group consisted of the mothers of 28 children with developmental disabilities. The results of the study revealed four main themes: 'The journey to acceptance,' 'The meaning/purpose of life,' 'Concerns about the future,' and 'Coping strategies.' The results of the study showed that mothers of children with developmental disabilities in Turkey often use spirituality as a coping method. Using spirituality, they were able to handle the stress of their new lives. They began to see their children as giving meaning/purpose to their lives and experienced enhanced feelings of love/commitment. The mothers were most concerned about the fate of their children after the parents had passed away.

Keywords: child, coping strategy, developmental disability, mother, nursing, spirituality

Introduction

Developmental disabilities are defined as 'a group of chronic diseases that emerge in connection to mental and/or physical disorders, and usually continue for a life-time' (Connolly 2006). Developmental disabilities occur as cognitive (mental disability), physical (cerebral palsy), linguistic, social (autism), emotional, and behavioral (Eapen 2014). These children face limitations in basic life activities such as personal care, language, learning, and motor skills. For this reason, they may require specialized care, treatment, or other support services that are planned and coordinated in a customized way for long periods of time, or for the rest of their lives (Connolly 2006, Gallagher *et al.* 2015).

Parents of children with developmental disabilities experience more financial and psychological difficulties than parents of healthy children (Dereli and Okur 2008, Gallagher *et al.* 2015, Khamis 2007, Masulani-Mwale *et al.* 2016). Parents have difficulties adjusting to their changing roles and responsibilities in family life. This generates stress for the entire family, especially for the mothers, who experience high levels of stress and anxiety. Previous studies have shown that mothers generally take responsibility for the care of children with disabilities, and as a result, they have higher stress, depression,

and anxiety levels than other family members (Dereli and Okur 2008, Eapen 2014, Scharer *et al.* 2009, Yildirim *et al.* 2012).

Mothers use various strategies to cope with stress and anxiety (Khamis 2007, Pandya 2017, Scharer *et al.* 2009). Some mothers benefit from community services, whereas others seek support by relying on their families or religion (Goldberg *et al.* 2014). A person's values and beliefs, particularly the sub-element of spirituality, can be important for coping with experiences that push the boundaries in life (Hicdurmaz and Oz 2013). The spiritual dimension emerges during crisis situations such as disease, stress, and fear of death, which prompt an individual to question the meaning of life and to lose hope. Spirituality often increases in mothers of children with developmental disabilities who are suffering from despair (Cinar and Eti-Aslan 2017). Spirituality encompasses moral values and religious beliefs and is an instrument that mothers of children with developmental disabilities can use to help them understand and accept their current situation. Spirituality provides explanations for the meaning of life and helps believers gain confidence (Dogan 2016).

The word 'spirituality' is associated historically with concepts such as religion, beliefs, mores, and includes a wide range of meanings. Today, it encompasses a broader concept beyond that of religious beliefs. In addition to

Correspondence to: Aysel Karaca, Duzce University, Faculty of Health Science, Duzce 81620, Turkey. E-mail: ayselkaraca0905@gmail.com

seeking a relationship with a heavenly spirit, spirituality also includes elements that address the meaning of life (Cinar and Eti-Aslan 2017). It represents an effort toward understanding and accepting the relationship between oneself and others, one's place in the universe and the meaning of life. It is the result of lifelong acquired information and includes elements regarding the purpose of life that are meaningful to the individual (Arslan and Konuk Sener 2009, Cinar and Eti-Aslan 2017, Kostak 2007).

Comparative studies of families of children with developmental disabilities assessing cultural/ethnic differences have shown that religion and spirituality are significant coping strategies for family adaptation.

Studies from other countries have also found that spirituality was the most effective coping strategy (Duvdevany and Vudinsky, 2005, Gallagher *et al.* 2015, Khamis 2007, Skinner *et al.* 2001).

Parents having difficulties coping with psychosocial issues need mental health services. However, adequate services are generally unavailable (Masulani-Mwale *et al.* 2016). Doctors, nurses, social service specialists, and psychologists may have important roles in providing parents with the needed mental health support. Nurses who work in hospitals, schools for children with mental or physical disabilities, and rehabilitation centers should evaluate these children and their parents comprehensively.

Spiritual needs vary depending on conditions and cultural structures (Kara 2008, Ozpak *et al.* 2017). Studies conducted in Muslim countries have shown that spiritual needs are affected by religion and beliefs. Parents were found to observe absolute obedience arising from their belief in Allah, thus acquiring mental and spiritual health and balance. Believers know that even the worst conditions result from the will of Allah and that they are being tested and consequently, they remain obedient to Allah. Thus, they never give way to despair and anxiety (Al-Kandari *et al.* 2017, Balubaid and Sahab 2017, Kara 2018).

Studies that examine the coping strategies of mothers of children with developmental disabilities in Turkey are limited. These have shown that spirituality was frequently used as a coping strategy (Dogan 2016, Goren 2015, Kara 2018). However, no qualitative study conducted using in-depth interviews is to be found in the literature. Accordingly, this study was designed to assess the coping strategies of mothers of children with developmental disabilities and to determine how they use spirituality as a coping strategy.

Methods

Design

This study evaluated the spiritual needs of mothers of children with developmental disabilities and analyzed the effect of spirituality as a coping strategy on their lives. In-depth qualitative interviews enabled the

researchers to obtain deep insight into the mothers' experiences and the effects of the coping strategy on their lives. The technique also gave mothers a high degree of freedom to respond to questions, elaborate on their ideas and feelings, and illustrate concepts (Morse and Field 1995).

Sampling

The population of this study consisted of mothers of children with developmental disabilities attending the School for Children with Mental and Physical Disabilities in Turkey. In total, 131 children diagnosed with mental disability, hydrocephalus, Down's syndrome, and cerebral palsy were being educated at the school. Mothers of the children with developmental disabilities were usually present at the school to support the care of their children. The mothers fulfilled their children's basic needs (toilet, food, diaper changing, etc.) during the children's break time and could relax in the lounge designed for them while their children were in the classroom. When the study was carried out, 31 mothers were present at the school accompanying their children. The researchers held a meeting with the mothers in the lounge and explained the aim and content of the study to them. Two of the mothers declined to participate and one mother was leaving the school because she had relocated. The study was finalized with 28 volunteer mothers. The thoughts of these 28 mothers included in the study were addressed and assessed as one group.

Data collection tools

The data of this study were generated using a personal information form and a sub-structured qualitative interview form.

Demographic information form

This form was created by the researchers based on a review of the relevant literature. It sought information about the sociodemographic features of the mothers including age, education level, number of children, and the diagnoses and duration of their children's developmental disabilities.

Qualitative interview form

The study used a semi-structured form created by the researchers to guide and lead the interviews. Open-ended questions were included to determine participants' emotions, opinions, perceptions, and attitudes about the subject of the study. The interview form was created after a wide-scale review of the relevant literature. To ensure the content validity of the form, the researchers consulted five experts with PhD degrees in educational sciences, psychiatric nursing, and pediatric and public health. After obtaining these professional opinions, one question was added to the interview form. Some

examples from the interview included: ‘Do you have spiritual values/beliefs that help you cope with hardships?’ ‘What makes your life meaningful?’ ‘What is the meaning of life?’ ‘Did your moral values/beliefs help you cope with your child’s developmental disabilities?’ ‘Did you take support from your religious beliefs and practices during this period?’ ‘Did you do or consider doing one or more of these practices: visiting a shrine, using charms, praying, making votive offerings, consulting a hodja (Muslim religious advisor), etc. during this period?’ The 12 items on the form were not used in any specific order but followed the flow of the interviews.

Data collection

The data were collected in June 2018 using comprehensive interviews as a qualitative research method. The researchers conducted interviews individually. Appointments were arranged with the mothers and interviews were carried out in the office of the school psychologist. First, the interviewer explained the purpose of the interview to the participant and then provided information about the duration, the reason for the audio recording, and assurances of the confidentiality of all the data obtained from the interview. The participants were reminded that they could turn off the audio recorder whenever they pleased. The interviewer took observational notes about the behavior of participants during the interview. The interviews lasted approximately 45 min for each participant.

Data analysis

Thematic analysis and stages based on the principle of similarity and mutual points were used for the data analysis (Braun and Clarke 2006). In the first stage, all the data collected in writing or verbally for each question on the semi-structured interview form and observational notes from the interviewer were uploaded directly to computers without any changes. The suitability of the opinions and notes were reviewed and opinions deviating from the study purpose were not documented. In the second stage, the opinions were combined according to their semantic similarities, code names were created, and the frequency of each combination of opinions was assessed for each code. In the third stage, the codes were grouped according to their underlying meanings and theme names representing these codes were generated. In the fourth stage, the researchers generated the codes and themes independently to increase the reliability of the data analysis. Afterwards, they had compared codes and reached a consensus, to ensure the validity of the data analysis, the researchers also consulted an expert and three research participants, who were asked if the codes and themes designated by the researchers were suitable. The tables were then finalized based on

their opinions (Yildirim and Simsek 2008). This report was written as the final stage of the data analysis.

Ethical considerations

Written permission (Number: 2018/13) was received from the Düzce University Ethics Committee for Clinical Studies prior to conducting the research. After informing the mothers and nurses about the research, written permission was obtained from those who voluntarily agreed to participate in the study. It was explained to the mothers that interview data and personal identity information would remain confidential.

Findings

Demographic characteristics

The mean age of the mothers participating in this study was 36.9 years; 25% of the mothers were high-school graduates, 55% were primary-school graduates, and 20% were university graduates. All the mothers in the study were housewives and 41% of them had middle-range incomes (incomes equal to expenses).

The children were between the ages of 8 and 17 years (8–10, $n=5$; 10–12, $n=4$; 12–14, $n=9$; 14–17, $n=10$). The age of the children when diagnosed ranged from birth to nine months. The conditions diagnosed in the children included Down's syndrome, mental disability, cerebral palsy, and hydrocephalus. The IQ levels of the children were between 20 and 35.

Major categories and subcategories identified

After the thematic analysis, the statements of the mothers were gathered under the specified categories (Table 1).

Main theme 1. The journey to acceptance

All the mothers interviewed ($n=28$) stated that the emotions and opinions they had expressed when their children were first diagnosed markedly differed from their current emotions, opinions, and perceptions. The results of the interviews also showed that the mothers had gone through a process to accept the diagnoses of their children and adapt to living with them. The journey to acceptance for the mothers is explained using three sub-themes.

Sub-theme 1. First confrontation

In this sub-theme, the mothers stated they had felt great sadness when their child was first diagnosed. Almost all the mothers ($n=26$) mentioned they had not wanted to believe their children had developmental disabilities and had continuously sought the answer as to why it happened this way. Most mothers ($n=26$) stated that they had rebelled in the early years. Some ($n=11$) thought they had been punished by Allah and others ($n=10$) questioned why such a hardship had been given to them. During the interviewing process, mothers had difficulties in expressing the feelings they

Table 1 Major categories and codes

Major categories	Codes
<i>Main theme 1. The journey to acceptance.</i>	
Sub-theme 1. First confrontation.	Shock and disbelief. Feeling like the entire world is crashing down around her. Rebelling Not meeting anyone because she feels ashamed of her child. The question of 'Why me?'
Sub-theme 2. The season of depression/sorrow.	Always looking for someone to blame. The thought of having made a mistake or being punished. Excessive denial. Neglecting one's personal care. Decreasing care for the child.
Sub-theme 3. The season of finding meaning.	Diagnosis of depression. Inability to sleep. Usage of strong depression medication. Physical problems (diabetes, heart disease, blood pressure problems, etc.).
<i>Main theme 2. The meaning/purpose of life</i>	
Sub-theme 1. Devoted lives.	The thought of being chosen. Describing her situation as destiny/fate. Describing her situation as a test. The thought of receiving a reward in the future. Opposing the idea of being tested or rewarded. Defining the child as the meaning of one's life. The thought that she would not be able to breathe without the child. Being proud of her child. Being willing to abandon her own life for the child. The thought of never being able to be separated from the child. Not enjoying time away from the child. The feeling of emptiness without the child. The thought of growing together with her child.
Sub-theme 2. Growing with the child and learning about life from the child.	
<i>Main theme 3. Concerns regarding the future.</i>	
Sub-theme 1. What if I die before my child ?	The thought of maturing due to this experience. Realization of the change in her perception of life. The thought of having learned patience. Realization of her own power.
Sub-theme 2. If I had three wishes ...	The thought that care for the child would not be provided by someone else. The fear of dying before the child. The wish for her child to be able to speak. The wish for her child to be able to walk. The wish for her child to be able to care for himself/herself. The wish for her child to be able to express himself/herself.
<i>Main theme 4. Coping strategies.</i>	Praying, performing 'namaz' (obligatory ritual prayer), and reading the Quran. Relying on Allah. Engaging in handicrafts, cooking, and reading. Walking or taking a shower. Being present at the school.

described as 'rebellion,' but with the help of the interviewer, they were able to do so. Many of the mothers ($n=19$) became emotional and cried while talking about those moments.

One mother of a child with severe developmental disabilities (cleft palate/lip) commented about her acceptance of the hardships:

'I got so confused... (She is crying.) I was trying so hard to hide and not let anyone see my child. When someone came, I never let my child out of the bedroom. I did not want them to see. For four years, I did not take my child outside other than to the hospital' (Participant 13).

Mothers also expressed feelings of rebellion:

'At first, I was so rebellious! I'm so regretful right now since I rebelled. What I complained about the most was "Why me! Why is my son like this?"' (Participant 15).

'I said, "Why, God?" I rebelled against God, but then I got used to the situation. I regretted what I had said and vowed not to do it again' (Participant 10).

The emotions that mothers felt when they learned about the diagnoses of their children included:

'It was so hard... (Talking tearfully, with no eye contact). It is like you are living in a nightmare, not in a dream, but when you are awake. I think I lost myself when I was listening to the doctor ...' (Participant 5).

Some mothers interpreted their child's illness as a punishment for themselves. For example:

'We are a huge family. My husband has five siblings and I have six siblings. I asked, "Why me among them?" I wondered if it was penance for a mistake or a sin of mine. At first, I always asked myself about it ...' (Participant 20).

Sub-theme 2. The season of depression/sorrow

All mothers except three described the first years after they learned about the diagnoses of their children as mournful, anxious, and dark days. More than half of the mothers ($n=16$) reported that they had been in denial throughout those years and did nothing other than

necessary duties, while neglecting to care for the other children in the home. Some of the mothers ($n = 12$) stated they had fallen into depression and had taken prescribed antidepressant medications. Four of the mothers had been diagnosed with heart disease, six with diabetes, and four with hypertension.

'Back then I was taking the medications given to me by the psychiatrist... My opinions were changing so much when I did not take them. I wished to die right away and be freed from this... In other words, I did not care about anything...' (Participant 2).

'I was eaten away during that period... I got diabetes. I had a stomach hernia and became neurasthenic... I used medications and antidepressant pills. I would be so angry when I did not use them. Sometimes I felt like destroying B...' (Participant 17).

Sub-theme 3. The season of finding meaning again

In this theme, all the mothers stated that they had adapted to the disabilities of their children and that they interpreted this experience differently now. Thus, some mothers thought they had found the answer to the 'why' question they had asked when first confronted with the diagnoses of their children. Many of the mothers ($n = 22$) described their children's disabilities as Allah's will or destiny/fate. Some mothers ($n = 17$) explained that this experience was a test, some ($n = 12$) said they would be rewarded if they passed this test, and some ($n = 10$) stated that they were special people who had been chosen by Allah.

The two quotations below are statements from mothers who thought they were chosen people:

'Allah gave my child to me, so it means that I have the necessary strength. Why did God choose me among other people and give him/her to me? It means that I am such a reliable person that my God trusted me with my child, and that I can take care of him/her very well' (Participant 4).

'My daughter is a special child for us. I mean, my God chose me. I think I and my husband were chosen. It means that we are worthy of her. I started to think that I could cope with it' (Participant 8).

The two quotations below are from mothers who perceived this experience as a test from Allah:

'I think he/she is an angel, not committing any sin, not responsible for anything that he/she does, and if I take care of him/her and am patient, maybe I will go to heaven' (Participant 14).

'I perceive this as a test. I never think that if I get through this, I will get a reward, because we are still in this test...' (Participant 2).

The quote below is a striking statement against the perception that a child with developmental disabilities is a test or chance to go to Heaven:

'I get so angry when people say, "He/she is a test for you, your chance for heaven." It is as if I got so tired and ashamed of my child that I could not handle it any more- that I only take care of my child to pass a test or go to heaven ...' (Participant 16).

The quote below shows the current stage of a mother in her journey to acceptance:

'I, who did not take her child outside due to embarrassment, go everywhere with my daughter now... For instance, we go to the market, to dinner, and for shopping. I feel like I have passed through a huge, dark period' (Participant 13).

More than half of the mothers ($n = 17$) stated that, even though they had accepted this situation, during some periods in their children's lives (starting school, etc.) they felt a great sadness when comparing their children with their peers. One of these statements is given below:

'Sometimes I wish my child were normal. He/she would be finishing the third grade. He/she would take exams, pass tests, or maybe he/she would find a poem or a story in a Turkish schoolbook and would read it to me. At those times I feel the same pain as in the first days...' (Participant 26).

Main theme 2. The meaning/purpose of life

In this theme, the meaning the mothers attributed to life with their children and their disabilities was evaluated. All the mothers explained that caring for their children encompassed their whole lives and time spent on themselves was limited. Mothers also reported that they had been given a chance to rediscover life from this experience. The two sub-themes below give important information about the perceptions of the mothers and the meaning they attributed to this experience:

Sub-theme 1. A life devoted to her child

All mothers stated they were happy to have their children with developmental disabilities in their lives. Mothers reported that they spent each moment with their children and that it was as if their children were a part of their own bodies. They felt like they would not be able to breathe without them and they had no expectations for their own lives. Furthermore, almost all mothers stated that they loved the child with disabilities more than their other children but that they could not articulate this love.

The quotations below include mothers striking statements about their love towards their children:

'He/she is like water on our table, salt in our food, and life, blood in our veins and our hearts. I mean we are fortunate to have him/her' (Participant 22).

'I love my son so much, since I, not anyone else, am the mother of A... It is rather pleasant for me to live with him. I wake him up even when he sleeps early. I say "wake up" ... He does not talk right now. He can't talk, but even when he sits silently, he fills that huge house. His love is such a different thing' (Participant 4).

'I am so grateful that I have him/her, that Allah destined him/her for me. It is not something you can explain - it has so many good sides... I live every moment with him/her to the fullest. Sometimes I hug him/her and say, "What would I do if I did not have you?"' (Participant 11).

Sub-theme 2. Growing with her child, learning about life from her child

All mothers stated that having a child with developmental disabilities had provided a positive contribution to their lives and that they had learned many things from their children. Many mothers ($n=21$) stated that the experience had changed their perception of life. Some mothers ($n=11$) stated that they had matured and others ($n=13$) reported that they had realized their strengths. During the interviews, when mothers were talking about the transformation of their lives, they sounded powerful, made eye contact, and smiled often.

Some of these statements are given in the quotations below:

'Now I have more say in the decisions concerning me and my son. I do not let anyone else decide for me anymore!' (Participant 13).

'I grew up with E... I got through adolescence, I mean that development period (all my problems), with him. I think about it now. Could I get this mature without my son? Could I be this strong? ... I do not think so ...' (Participant 3).

'B... taught me how strong I am. B... taught me how patient I am. B... taught me how I should defend my child in society. When I teach B... I realize that I have also learned so much from B...' (Participant 19).

'Of course, my life has changed drastically. Before my child, I was a person who was not satisfied with anything, always seeking more or getting bored quickly. But now I get so happy from the littlest thing and I have learned to be content with what I have' (Participant 20).

More than half of the mothers ($n=17$) stated that this life made them stronger, but they also said that this strength was necessary for them to take care of their children. Some of these statements are:

'I try not to make myself miserable like before. I can say "no" when necessary because my son needs me ...'

'I have to stand tall because if I fall, if I do not make an effort and have psychological problems, how can I take care of my child? ... For this reason, I am not concerned about the past and the unimportant details. I do anything to keep myself steady.'

Main theme 3. Concerns regarding the future

All the mothers expressed their concerns about their children's future during the interviews. The source of the mothers concerns is explained in the sub-themes below:

Sub-theme 1. What if I die before my child?

One of the conclusions obtained from the interviews was that almost all responsibility for taking care of children was shouldered by the mothers. All the mothers thought that no one else could take care of their children or no one else would take over the responsibility for their care. It can be dramatically seen in the statements below that these opinions caused great concern for the mothers.

'No one would take care of him/her like me. Does a person want her child to die? But I hope that Allah does not let him/her live after me. I hope that either he/she dies before me or we both die at the same time. I do not want my child to live after I die. It is so hard ...' (She is crying.) ... (Participant 8).

'If I die before my child, I would call him/her with my last breath. I pray like "dear Allah, let him/her die with me. Do not leave him/her behind and make me die in distress". Otherwise, I would die in distress ...' (Participant 13).

Sub-theme 2. If I had three wishes ...

All the concerns of the mothers were related to their children's future. Some mothers wished for their children to be able speak, whereas some ($n=7$) wished for them to be able to eat on their own and others ($n=9$) wished for their children to be able to walk. None of the mothers wished anything for themselves or their other children.

'If I had a magic wand in my hands ... I would wish for my daughter to at least be able to talk, and for her to be calmer' (Participant 8).

'My biggest wish is that my child not be left behind after me. All mothers of children with developmental disabilities pray for this' (Participant 13).

Main theme 4. Coping strategies

All the mothers interviewed stated that they could not spare time for themselves because they spent most of their time with their children. Nevertheless, a vast majority of the mothers ($n=25$) stated that praying and reading the Quran comforted them. In addition, while a few of the mothers ($n=3$) stated that handicrafts relaxed them, others said that walking ($n=2$), or cooking ($n=5$) was soothing for them.

'I simply pray at any moment. I read the Quran when I get the chance. It makes me feel calm' (Participant 5).

'The only thing that comforts me is praying. Sometimes at night I wake up and pray. And I recite with my prayer beads all the time' (Participant 21).

Almost all the mothers stated that starting at the school for children with developmental disabilities had a positive influence on both them and their children. The quotation below discusses how this school has contributed to mothers coping with this experience:

'When I look at the past, the school has affected us in a very positive way because there are similar people around us who can understand us. When you tell some outsider, it is so hard for them to understand you since they do not have a child like yours. They have not experienced anything like this ... You don't even need to talk with the mothers at the school since you see what they are going through. This place has really done some good for my depression' (Participant 3).

Discussion

This study was conducted to evaluate the spiritual needs of mothers of children with developmental disabilities

and to analyze the effect of spirituality in their lives as a coping strategy.

Acceptance and unconditional love

Families may go through shock, denial, depression, guilt, shame, refusal, and anger when they first learn about the developmental disabilities of their child and sometimes, they may believe that this situation is a punishment for them (Goldberg *et al.* 2014, Yildirim *et al.* 2012). The mothers in this study had experienced complex emotions (e.g. shock, denial, not going outside of the house, or not showing her child to anyone) when they first learned about the condition of their children and 43% had received treatment for depression or had faced physical health problems. Nevertheless, analysis of their current emotions and opinions showed that they loved their children dearly and that they were very attached to each other. They expressed these emotions and opinions with the words, 'I love my child with developmental disabilities more than my other children,' 'We are like conjoined twins,' and 'I feel uneasy if I leave him/her'. Thus, the acceptance process may continue for years and some mothers in this research group were still on the journey to acceptance, taking into consideration that the youngest child of the mothers in the study was eight years old.

A review of the relevant literature about the parents' acceptance of their child and the attachment between them revealed that some studies had reached different conclusions. Other studies have shown that families of children with developmental disabilities had difficulty accepting the situation and experienced hardships due to deterioration of their family and social relationships, exhaustion, financial problems, guilt, and inadequate social support (Dereli and Okur 2008, Eapen 2014, Scharer *et al.* 2009, Yildirim *et al.* 2012). Studies in Uganda, Kenya, and Nigeria have revealed that disability was perceived as a result of adultery, witchcraft, a curse, a punishment inflicted by God for sins committed, or the work of evil spirits (Etieyibo and Omiegbe 2016, Gona *et al.* 2011, Hartley *et al.* 2005, Nyangweso 2018).

However, some studies demonstrated that providing care for children with developmental disabilities also had positive and satisfying aspects and that this situation may have been generated from the mothers psychological strength, positive family relations, and strong spiritual values and beliefs (Schwartz and Tsumi, 2003, Seltzer *et al.* 2001). Spirituality might be morally supportive for mothers of children with developmental disabilities (Cinar and Eti-Aslan 2017). This support has helped mothers to see their child not as a burden, but as a blessing, or to believe that their faith was being tested (Schwartz and Tsumi 2003). Meeting spiritual obligations helps mothers accept the situation and plan for the future, thereby affecting mothers positively by increasing hope in their lives (Cinar and Eti-Aslan 2017, Kara

2008). In the current study, the mothers thought of themselves as 'chosen' and their children as 'blessings' given to them and they interpreted this situation as a 'test'. These thoughts affected the acceptance period positively and enhanced the mothers commitment to their children.

However, a few mothers ($n=2$) stated that they did not see their children with developmental disabilities as a test or a chance to go to heaven but loved them unconditionally. They expressed these emotions with this statement: 'I get so angry with statements like he/she is your test, your chance to go to heaven ... It is as if I got so tired and ashamed of my child that I could not handle it anymore, and that I only take care of my child to pass a test or go to heaven.' When the child was first born, these mothers went through complex emotions like shock, denial, and refusal. However, they now love their children and are closely attached to them, which emanates from unconditional love, a spiritual element.

Another finding of the research was that mothers see their children with developmental disabilities as giving meaning or purpose to their lives. Mothers expressed their emotions with these words: 'My child is my everything. I cannot breathe without him/her. He/she is the center of my life. My child is the meaning of my life.' Mothers stated that their children with developmental disabilities had helped them to mature and develop their personalities and that their perspectives on life had changed as well. Apart from seeking a relationship with a holy spirit, spirituality also includes hope, love, comfort, and affection, which constitute the meaning of life (Arslan and Konuk Sener 2009, Cinar and Eti-Aslan 2017, Kostak 2007). In this study, all the mothers had used elements of spirituality during the acceptance process, especially that of unconditional love.

Coping

People marginalized by society in various ways and unable to overcome these barriers are left in despair. However, they often find solace in Allah and renew their hope and trust by embracing religion. Religion is morally supportive of families with children with developmental disabilities (Dogan 2016). People turn to religion under difficult conditions and are able to persevere in life because of their religious beliefs. Embracing the power of religion and praying under negative conditions helps people to feel virtuous and to gain positive attitudes. In this study, mothers frequently prayed and turned to Allah as a coping strategy.

Similar results have been obtained by other studies, and spiritual coping is used in all cultures. Studies conducted in Muslim countries have shown that parents frequently use spirituality as a coping strategy (Goren 2015, Kara 2008, Ozpak *et al.* 2017). Studies conducted in Saudi and in northern Jordan have shown that the most

common coping strategies are reading the Quran, praying and drinking 'Zam-Zam' water (from the holy well in Mecca; Alrowais and Alyousefi 2017, Aburahma *et al.* 2010). Religious beliefs are a source of refuge and consolation for many people after sudden changes in the natural flow of life or traumatic events. Additionally, performing 'namaz' (obligatory ritual prayers), reading the Quran, reciting with prayer beads, and praying are thought to calm mothers since in Turkey, causes and treatments for developmental disabilities can easily be associated with moral incidents. Studies conducted in various countries have also shown that spirituality is used as an effective coping strategy in Christian and Jewish societies. Large-scale studies (Pandya 2017) conducted in Israel (Duvdevany and Vudinsky 2005), Mexico, and Puerto Rico (Skinner *et al.*, 2001) and in the USA, Australia, Canada, and numerous European countries have found that spirituality is the most effective coping strategy used by parents.

Concerns

'The utmost fear of a mother is the death of her child before her, while the utmost fear of the mother of a child with developmental disabilities is the death of herself before her child.' The most worrisome situation for parents of children with developmental disabilities is the thought of 'what would happen to the child after their death.' For this reason, within the bounds of possibilities, parents try to arrange a secure future and ensure a safe workplace and social environment to guarantee the future of their children (Dogan 2016). According to the data acquired from this study, all the interviewed mothers had serious concerns related to the future of their children. Parents had concerns about what would happen to their children if their children outlived them because their support and protection would disappear. All the mothers in the study had concerns regarding their children being left alone after their death, being dependent on other people all their lives, and there being no one else willing to take care of their children. For this reason, it stood out that the mothers were quite concerned about their children's financial and moral future.

When findings of comparable studies in the literature were examined, results were found to be similar. Yazici *et al.* (2015) assessed visually impaired children in Turkey and found that the mothers were quite worried that after they died, their children might be put in a difficult situation. Chang and McConkey (2008) reported that parents in Taiwan were pessimistic about the future of their children and they stated that the social system was incapable of caring for the children after the death of their parents. In addition, most parents stated that the other significant issue they were concerned about was that their children might be physically, emotionally, or sexually abused by other people (Chang and McConkey 2008). Holroyd (2003) found that mothers of children

with developmental disabilities in China were concerned about their children being taken care of by someone who 'does not love him/her or is forced to take care of him/her' (Holroyd 2003).

When the results of the research were analyzed, the concerns of the parents scored high because the employment and independent living services for children with developmental disabilities have not improved in developing countries like Turkey. If services for those with disabilities were improved and promoted, these concerns and worries might decrease. Improving health services by addressing the psychosocial needs of parents of children with developmental disabilities might reduce the parents' worries and anxiety. Individual and group therapy to reduce anxiety levels of the mothers and improve their coping skills are recommended.

Conclusion

The results of the study indicated four main themes: 'The journey to acceptance,' 'The meaning/purpose of life,' 'Concerns about the future,' and 'Coping strategies.' This study showed that mothers of children with developmental disabilities in Turkey often use spirituality as a coping strategy. Mothers of children with developmental disabilities whose lives had suddenly changed in an undesired way had experienced numerous upsetting and complex emotions. These mothers used spirituality as a coping mechanism for adjusting to these sudden life changes and resolving problems. By virtue of spirituality, they were able to survive the troublesome days and cope with the stress of their new lives. They began to see their children as giving meaning to their lives, experienced enhanced feelings of love for their children, and commitment to each other.

In addition, these mothers of children with developmental disabilities had serious concerns related to the child's future. In accordance with the concerns of the mothers, it is essential to assure provisions for those with disabilities, especially those whose disabilities are too severe to allow them to live on their own. Accordingly, researchers should assess individuals in all disability groups along with their parents. All problems should be detected, and solution-oriented policies should be developed in cooperation with governmental agencies.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Aysel Karaca  <http://orcid.org/0000-0003-4507-0726>

References

- Aburahma, S. K., Khader, Y. S., Alzoubi, K. and Sawalha, N. 2010. Complementary and alternative medicine use in a pediatric neurology clinic. *Complementary Therapies in Clinical Practice*, 16(3), 117–20.

- Alrowais, N. A. and Alyousefi, N. A. 2017. The prevalence extent of complementary and alternative medicine (CAM) use among Saudis. *Saudi Pharmaceutical Journal*, 25, 306–318.
- Al-Kandari, S., Alsalem, A., Abohaimed, S., Al-Orf, F., Al-Zoubi, M., Al-Sabah, R. and Shah, N. 2017. Brief report: social support and coping strategies of mothers of children suffering from ASD in Kuwait. *Journal of Autism and Developmental Disorders*, 47, 3311–3319.
- Arslan, H. and Konuk Sener, D. 2009. Studying the concepts of stigma, spirituality and comfort in accordance with meileis concept development process. *Maltepe Üniversitesi Hemşirelik Bilim ve Sanatı Dergisi*, 2, 51–58.
- Balubaid, R. and Sahab, L. 2017. The coping strategies used by parents of children with autism in Saudi Arabia. *Journal of Education and Practice*, 8, 141–151.
- Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Chang, M. Y. and McConkey, R. 2008. The perceptions and experiences of Taiwanese parents who have children with an intellectual disability. *International Journal of Disability, Development and Education*, 55, 27–41.
- Cinar, F. and Eti-Aslan, F. 2017. Spiritualism and nursing: the importance of spiritual care in intensive care patients. *Journal of Academic Research in Nursing*, 1, 37–42.
- Connolly, B.H. 2006. Issues in aging in individuals with life long disabilities. *Revista Brasileira de Fisioterapia*, 10, 249–262.
- Dereli, F. and Okur, S. 2008. Determination of the depression level of the families having a handicapped children. *The New Journal of Medicine*, 25, 164–168.
- Dogan, M. (2016). The comparison of parents with disabled children and parents with healthy children in terms of their levels of religious coping, hope and patience. *Journal of Human and Social Sciences Research*, 5, 3214–3245.
- Duvdevany, I. and Vudinsky, H. 2005. Out-of-home placement of children with intellectual disability: Israeli-born parents vs. new immigrants from the ex-USSR. *International Journal of Rehabilitation Research*, 28, 321–330.
- Eapen, V. 2014. Developmental and mental health disorders: two sides of the same coin. *Asian Journal of Psychiatry*, 8, 7–11.
- Etiyibo, E. and Omiegbe, O. 2016. Religion, culture, and discrimination against persons with disabilities in Nigeria. *African Journal of Disability*, 5, 192–198.
- Gallagher, S., Phillips, A. C., Lee, H. and Carroll, D. 2015. The association between spirituality and depression in parents caring for children with developmental disabilities: social support and/or last resort. *Journal of Religion and Health*, 54, 358–70.
- Goldberg, D., Fontil, L., Sladeczek, I. and Miodrag, N. 2014. Coping strategies and implications of disability in parents of children with autism versus down syndrome – two different sides of the same coin? *MindPad*, 4, 23–26.
- Gona, J. K., Mung'ala-Odera, V., Newton, C., R. and Hartley, S. 2011. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child: Care, Health and Development*, 37, 175–183.
- Goren, AB. 2015. Assessing the needs and sources of support of mothers with down syndrome child. *Journal of the Human and Social Sciences Researches*, 4, 651–673.
- Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M. and Chavuta, A. 2005. How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development*, 31, 167–180.
- Hicdurmaz, D. and Oz, F. 2013. Spirituality as a dimension of coping. *Journal of Anatolia Nursing and Health Sciences*, 16, 50–56.
- Holroyd, E. E. 2003. Chinese cultural influences on parental caregiving obligations toward children with disabilities. *Qualitative Health Research*, 13, 4–19.
- Kara, E. 2008. The parents having mentally retarded children and their assessment of their children's situation in terms of religion. *Ondokuz Mayıs University Review of the Faculty of Divinity*, 26, 317–331.
- Kara, E. 2018. Empowerment implementation with mental support for mother with handicapped children. *The Journal of International Social Research*, 11, 311–322.
- Khamis, V. 2007. Psychological distress among parents of children with mental retardation in the United Arab Emirates. *Social Science and Medicine*, 64, 850–857.
- Kostak, M.A. 2007. Spiritual aspects of nursing care. *Firat Sağlık Hizmetleri Dergisi*, 2, 105–115.
- Masulani-Mwale, C., Mathanga, D., Silungwe, D., Kauye, F. and Gladstone, M. 2016. Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? *Child: Care, Health and Development*, 42, 871–880.
- Morse, J.M. and Field, P.A. 1995. *Qualitative research methods for health professionals*. 2nd ed. London: Sage Publications.
- Nyangweso, M. 2018. Disability in Africa: a cultural/religious perspective. Available from: https://www.researchgate.net/publication/325642373_Disability_in_Africa_A_CulturalReligious_Perspective
- Ozpak, A. M., Tekin, O., Arslan, I., Gurhan, B., Ozdas, M. S., Celik, M., Arıman, O. O., Evmez, M. and Fidancı, I. (2017). Investigation of healthy living behaviors of parents with disabled children. *Konuralp Medical Journal*, 9, 12–19.
- Pandya, S. P. 2017. Spirituality and parents of children with disability: views of practitioners. *Journal of Disability & Religion*, 21, 64–83.
- Scharer, K., Colon, E., Moneyham, L., Hussey, J., Tavakoli, A. and Shugart, M. 2009. A comparison of two types of social support for mothers of mentally ill children. *Journal of Child and Adolescent Psychiatric Nursing*, 22, 86–98.
- Schwartz, C. and Tsumi, A. 2003. Parental involvement in the residential care of persons with intellectual disability: the impact of parents and residents characteristics and the process of relocation. *Journal of Applied Intellectual Disabilities*, 16, 285–293.
- Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y. and Hong, J. 2001. Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106, 265–286.
- Skinner, D. G., Correa, V., Skinner, M. and Bailey D. B. Jr. 2001. Role of religion in the lives of Latino families of young children with developmental delays. *American Journal of Mental Retardation*, 106, 297–313.
- Yazici, F., Okcu, B. and Sozibilir, M. 2015. Parents anxiety for their visually impaired children's future. *Ege Journal of Education*, 16, 142–164.
- Yildirim, A., Hacıhasanoğlu-Aşilar, R. and Karakurt, P. 2012. Determination of psychological status of mothers with disabled children. *İ.Ü.F.N. Hem. Derg.*, 20, 200–209.
- Yildirim, A. and Simsek, H. 2008. *Qualitative research methods in social sciences*. 7th ed. Ankara, Turkey: Seckin Publishing. pp. 72.